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Title: Why do staff and family think differently about quality of life in dementia? A qualitative study exploring perspectives in care homes.

Running title: Staff and family views on quality of life in dementia.

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Background: Quality of life is important especially in incurable illness. In dementia, we often need proxy reports of quality of life but we know little about how individuals make their judgements. In care homes, proxies may be staff providing care or relatives but staff rate quality of life differently to family. To our knowledge no-one has explored this qualitatively, so we used qualitative interviews to explore why staff and family think differently about quality of life.

Methods: We interviewed 12 staff and 12 relatives who had provided proxy ratings of quality of life for people living with dementia in care homes in the Managing Agitation and Raising Quality of life (MARQUE) study. We asked why they had rated the resident's quality of life as "Very Good, Good, Fair or Poor". Using thematic analysis, we compared staff and relatives' proxy responses.

Results: For staff, the concept of quality of life was often viewed synonymously with quality of care, influenced by their sense of responsibility and informed by their professional understanding. For relatives, quality of life was often judged in relation to how the person with dementia lived before diagnosis, and was influenced by their perception of loss for the person with dementia and their own adjustment.

Conclusions: Proxy reports were influenced by rater's own contexts and experiences. This can enhance our understanding of widely used research tools, aid the evaluation of intervention outcomes and indicate possible targets for improving perceived and actual quality of life of people with dementia.

Key words

Dementia

Carer

Quality of Life

Care Homes

Key Points

1. Staff and Family may conceptualize quality of life differently when providing proxy reports in dementia. A proxy rater's perception of quality of life is shaped by their caring experiences, their relational stance to the person living with dementia and their understanding of dementia.
2. Whilst differing proxy reports could be considered invalid, because they measure different variables than those directly associated with an individual's quality of life in dementia; they could also be appreciated as a valuable additional outcome: perceived quality of life.
3. Finding meaning in caring, accepting decisions, focusing on the present, coping with loss and better understanding dementia could improve caregiving experiences and improve perceived quality of life.

4. Proxy ratings of quality of life cannot be used interchangeably. Collecting the opinions of all key stakeholders in the resident's quality of life will maximize the chance of measuring improvements in care and quality of life

Introduction

Quality of life is an important outcome for people with dementia as the illness is chronic, deteriorating and incurable. Maintaining quality of life in dementia is possible, desirable and is the underpinning goal of care (1, 2). As global dementia care strategies focus on living well with dementia, finding a way to meaningfully measure quality of life is an area of research (3, 4).

Quality of life is usually understood as a broad, holistic construct (5) representing how "good" a person's life is overall (6). The World Health Organisation (1995) defines Quality of life as "an individual's perception of their position in life in the context of the culture and value systems in which they live and in relation to their goals, standards and concerns" (7). Quality of life is, at least in part, subjective and ideally reported by the individual concerned (6, 8, 9, 10, 11). However, many people living with dementia become unable to rate their own quality of life as dementia impacts a person's ability to understand abstract concepts, remember experiences and formulate answers.

Researchers often rely on a proxy informant to provide information about how the person *would* rate their own quality of life if they could. It is important that the proxy is somebody who knows the person well and is familiar with their everyday life (12). Proxies use this knowledge, alongside observations, to provide a rating. People living with dementia in care homes have more severe dementia than those in the community (13) and we often rely on proxies (14, 15). It is important to consider who provides this rating (16). Family members usually have a long-term perspective, while staff observe more of their day-to-day lives and functioning. The evaluated success of an intervention may depend on the perspective chosen (17, 18).

In the largest national care home study to date, we found staff systematically rated quality of life higher than family when providing quantitative proxy ratings for the same resident (19). For research findings, interventions and policy to be meaningful, we need to understand why proxy's views differ and what staff and family proxy reports are measuring (18, 19). For the first time using qualitative methods, we explored differences in staff and family proxy views about quality of life for people living with dementia in care homes.

Methods

This study is nested in Stream 2 of the Managing Agitation and Raising Quality of Life (MARQUE) national care home survey in England (20). MARQUE was approved by London (Harrow) NRES Committee (14/LO/0034).

Procedures

Relatives visiting most frequently and staff involved in hands-on care of the resident provided proxy ratings of quality of life using the DEMQOL-Proxy: a validated tool for proxy quality of life in dementia. SR invited participating relatives first and later the paired staff proxy to take part in a qualitative interview.

We sought a maximum variation sample to identify shared patterns that derive their significance by emerging from heterogeneity (21, 22). We recruited from a variety of care homes in London, Cambridge and Kent (voluntary, state and private) and care provision (nursing and residential). Within these, we sampled a range of socio-demographic characteristics: professional roles, time in role and relationships with residents. Some socio-demographic characteristics reflected frequency in care home (e.g., roles and gender (23)). We sampled staff and family pairs that had chosen the same quality of life global ratings and those that had not. We interviewed staff and relatives until we reached theoretical saturation and no new themes emerged (24).

SR conducted individual semi-structured interviews, to allow an in-depth focus on individual judgements (25, 26) in a private location chosen by the participant. Interviews lasted between 30 minutes and 80 minutes and were recorded, transcribed and anonymized. SR asked participants why they had chosen specific ratings of global quality of life. SR, CC and GL developed a topic guide with open questions to explore how the individual conceptualized quality of life in dementia (Appendix 1). We added questions from emerging themes to minimize hierarchical relationships and maximize the evocation of meaningful, personalized, lived experiences (27).

Analysis

We used Nvivo 11 to code and manage data. We analysed interviews using thematic analysis (28), employing a constant comparison method of coding and analysing data through three stages described by Starks (2007): “open coding” (examining, comparing, conceptualising, and categorising data); axial coding (reassembling data into groupings based on relationships and patterns among the categories identified in the data); and selective coding (identifying and describing the central phenomenon or “core category” in the data) (29, 30, 31). SR and KL completed open coding and axial coding first for relative interviews and then for staff. SR, KL and PR then completed selective coding, identifying and describing central phenomenon for staff and family interviews separately. We compared staff and family views in a thematic matrix and identified core categories accounting for different perspectives. All authors discussed themes together to resolve disagreement and ensure reliability. There were few disagreements, those that arose were related to text interpretation. We resolved these by focusing on what was described and revisiting the thematic matrix and lower level codes.

Results:

Demographics

We recruited 12 staff and 12 relatives from 7 care homes (1 nursing, 6 residential; 6 private, 1 charity). Staff and relatives’ characteristics are described in Tables 1 and 2.

Themes

We present the thematic matrix results visually in Figure 1. The diagram shows individual, relational and institutional factors mentioned by both staff and family. Thought bubbles represent factors specific to staff and family proxies. We will outline four key themes that we judged accounted for differences in perspectives:

1. Quality of Life = Quality of Care

Many staff conceptualized quality of life as quality of care. Staff often used “*care*” and “*life*” interchangeably and evidenced quality of life with example of good care. Some explicitly stated that quality of care determined quality of life:

If you are receiving a good quality of care then, still, you are living in a good quality of life.

Female Care Assistant [01]

Consequently, staff often viewed themselves as providers of quality of life:

The quality of life, it really solely depends on us, how we give it.

Female Care Assistant [02]

It's our major role... because we provide the best we can he has a good quality of life.

Female Care Assistant [01]

Some discussed how this helped them find meaning in their role:

*It's not necessarily job satisfaction but it makes you feel better... you're on shift for quite a long time and you need to feel as if you are doing a good job.
You need to feel as if you're making a difference really.*

Female Care Assistant [03]

For one staff member, this meant it was possible to choose a poor quality of life by not engaging with care. There was limited awareness that dementia may affect the ability to make a choice:

It's a poor quality of life but only because they choose to have that poor quality of life... why do you want to just sit in your room all alone... come out and interact with staff.

Male Senior Carer [13]

Ratings of quality of life, therefore, provided judgements on the care provided. One staff member reflected this may have affected their own evaluation:

I want to say everyone's got an amazing quality of life... it's upsetting as a carer to think that someone hasn't here, because you think is it something I'm doing?

Female Nurse [05]

One relative was explicit that staff did not always see the distinction between quality of life and quality of care:

They think he is being looked after so well so he must be all right. I don't think he is... I just said, hang on a minute, aren't we confusing quality of care with quality of life?

Son [14]

Some relatives acknowledged the impact care had on quality of life. Negative beliefs about living a care home often shaped these views:

He's not around me, so that's why I look at it every day "poor".

Wife [15]

To get the top box tick [Very Good] she would probably be wanting to live with me or my sister... I think fair is as good as we'd get.

Daughter [16]

For one relative, cultural expectations about where care should be provided shaped their evaluation:

I don't think most people would want to go in a care home. Culturally, it's not one of our things. We normally have elderly people at home.

Niece [17]

2. Comparing the past to the present

Relatives compared the person they saw now to the person they knew in the past. This centered on loss and led to negative evaluation of quality of life:

It's very hard because when I know what he used to be and what he is now... he has no life at all.

Niece [17]

He could read a book in a day and now he can't even hold a book.

Son [14]

Other times, relatives focused on past expressed wishes and conclusions; imagining what the person from the past would say if they saw themselves now:

He said "if I'm married to you and, say, for instance, I should take sick, please do not put me into a care home". I said to him, "But what about if I can't care for you, what should I do?". He said "Don't put me into a care home, I would rather to beg god to take me more than you put me into a care home". To know that now, he doesn't have the capacity and I made that decision...

Wife [18]

Both the resident and relative's own adjustment were important and some relatives focussed on how the resident was now:

In the early days, she did used to try to get out, but now in general, she's very contented here. I suppose you would say institutionalized, but to her it's a comfort, you know, and it is to me really.

Husband [19]

In contrast, staff usually only discussed a person's past in relation to improving care in the present. Staff talked about how getting to know a person empowered them to meet their needs by providing insights into their behaviours:

Knowing someone's past history helps us to define behaviours, feelings, their likes, their dislikes, how can I engage with them...? If you don't know, where do you go from?... you're in the dark.

Female Senior Carer [06]

3. Perceptions of dementia

Quality of life judgements were influenced by proxies' understanding of dementia. Relatives often discussed how dementia had changed a person. Maintaining the status as the same person was important for quality of life:

She's still, she's still there. She's still the same old cantankerous old sausage from time to time, but she's still, you know, NAME.

Son-in-law [20]

Sometimes this led to emotive discussions about their own loss of the person they knew:

Because I've lost my mum. My mum isn't there anymore. There's another person there and I still love her as my mum but it isn't my mum she's just been left to stagnate.

Daughter [22]

Relatives own projected fears of developing dementia were discussed when explaining their ratings:

Now that I have seen him with the dementia... I look for symptoms in myself... I hope I never get like him, I really do, I really do.

Son [14]

In contrast, staff were more likely to focus on their professional knowledge of dementia and the ways the dementia impacted a person's lived experience:

She's got the dementia where it's at the frontal lobe. That's what causes the anger issues.

Female Care Assistant [21]

Sometimes staff considered a progression of dementia as positive because people would be less likely to understand their situation or to worry.

NAME's one of our luckier ones with a better quality of life... her dementia is so severe she hasn't got a clue that she's got it.

Female Senior Carer [07]

Staff described how they had gained understanding through experience and training. They spoke of understanding what a person meant so they could meet their needs and provide quality of life:

At this moment in time she's clearly thinking she's a very young child and that's telling me she wants comfort... she's not able to say I want a cuddle, but she's able to say where's mum?... Giving her a cuddle, giving her some comfort is what she's looking for.

Female Care Assistant [06]

4. Relationships and systems supporting quality of life

Staff and relatives agreed on the importance of systemic influences but observed them from different positions. Relatives commented on the importance of good relationships between staff and the residents and the need for reciprocity:

The fact that he had and has retained, an extremely good sense of humour, which appeals to them, has paved the way, made the path easier... Because I think the carers, good and excellent though they may be, are only human.

Wife [15]

She's with a whole bunch of people who are always pleased to see her and always nice to her, she really likes it.

Daughter [21]

Related to this, staff gave examples of times they had got on well with residents as evidence of a person's good quality of life:

She's a joker which I think is very, very good because she interacts very, very well with staff. So, that's very important.

Male Care assistant [08]

He's really funny... it's nice and he does like affection... He'll even put his arm around you sometimes and give you a cheeky kiss on the cheek, so yes it's nice.

Female Care assistant [09]

Staff were more likely than relatives to talk positively about how relationships with family improve life quality:

Seeing family regularly, going out with family regularly... I can see what quality of life that brings to her.

Female Manager [10]

In contrast, when relatives discussed their own relationships with residents it more often alongside sadness and perceived redundancy:

There is a difference in his responses to his environment, which is positive and to me, who is almost like a stranger at times.

Wife [15]

I mean he doesn't know who I am... he just won't even acknowledge that I am there. I get blanked completely.

Son [14]

Staff and family discussed their relationship with each other. Staff talked about how communicating openly and honestly with families helped build trust and facilitate involvement which benefitted residents:

The key to a good quality of life in a care home is family involvement, don't shy away from telling families what's going on, and inform them before they find out for themselves... there's no shock when they come in.

Female Manager [10]

It was important for relatives to believe staff cared and find ways to cooperate and share knowledge for the resident's benefit:

Staff's first concern is that she's [resident] feeling as good as possible whereas I still tend to worry about things like, is she getting fat again?... Cooperation between me and staff has been quite important

Daughter [23]

I did ask the manageress if it was correct to bring him back to the present and say, "He died a long time ago". She said—which made sense—"don't keep giving him negative information"... And she was right.

Wife [15]

Both staff and family expressed worries about the organization of the workforce. Staff spoke about how limited resources negatively impacted quality of life:

You're so conscious of time... it's so easy to just take over... although we're there to promote independence I think sometimes we actually take it away...

Female Senior Carer [07]

Some relatives discussed how they observed the way care homes were run and the impact on quality of life:

Now there is a regional structure... the management structure gets bigger... authority gets more and more remote... all the care staff are unhappy and they're all being badly managed.

Daughter [23]

Discussion:

Different experiences provide different focuses

Relatives' longstanding personal relationships appear to influence their ratings. Knowledge of a person's past often provides family with positive memories that contrast with the present situation (32). Relatives may be influenced by a person's previously expressed wishes, spousal commitments and cultural expectations about care home placement. Relatives often need to

make stressful healthcare decisions against the wishes of the care recipient (33, 34) and it may be that the relatives' persisting unhappiness about these decisions affect perceived quality of life. Interventions may, therefore, never improve family perceptions of quality of life if the person with dementia remains in a care home. Staff, however, lack this longitudinal perspective on residents and are unlikely to have had a role in decision making.

Having a role in quality of life may be protective

For staff, actively providing quality of life may be viewed as a professional responsibility and something that adds value to their role (35). Caring self-conceptions may help staff move beyond the sadness experienced in their roles where they often work with little acknowledgement, for minimum wages and develop close relationships with individuals they care for until death (36). Having this role, ascribed purpose and perceived value in a resident's quality of life may provide meaning in caring which is protective and associated with higher caregiving satisfaction (37, 38, 39). Enabling carers to find meaning in their role whilst building or maintaining close relationships with residents may improve the caregiving experience and perhaps perceived quality of life. Improved communication and relationship quality between staff and residents has been associated with better perceived quality of life (40, 41). Improving relationships between proxy raters may also help facilitate collaborative care and help relatives find meaning in caring.

Adjusting to and coping with loss

When a family member moves to a care home, family carers may struggle to adjust to this transition. Relatives we interviewed rarely acknowledged their impact on a resident's life and a perceived redundancy may leave relatives feeling powerless (42). Family carer quality of life is poorer when people with dementia live in a care home despite reduced caring demands (43, 44, 45). Relatives are left adjusting to their own loss as their relationship to the person with dementia changes. Many relatives experience anticipatory grief: in advance of the loss of a significant person with a terminal illness, which may negatively impact their own quality of life (46). Poorer carer quality of life is associated with worse perceived quality of life in the person with dementia (43). The processes influencing relative proxy raters are more negative as they are jointly impacted by a higher emotional load of actual and imagined loss for the person with dementia and for themselves. Relatives' views of quality of life, and their own quality of life, may be improved if they are supported through the transition to find acceptance that their relative may be able to enjoy life despite the unchosen dementia.

Different understanding and insight

There is added complexity from an individual's interpretation of events. Illness representations influence a person's understanding of what is happening (47). Relatives are less likely than staff to be trained and understand dementia, so evaluation may be mainly about the person in the past and what has been lost. Staff may also lack understanding of a person's experience but may conceptualize quality of life as quality of care, which could lead to more positive evaluations.

Limitations

The care homes, staff and family consenting to this study may not cover the full range of experiences. A wider sample might identify additional factors influencing the perception of quality of life. Staff and family presented reflections on a single quality of life measure which may have restricted responses.

Future Research

Researchers may consider potential targets for improving perceived quality of life: enabling people to find meaning in their role; improving relationships; increasing understandings of dementia; facilitating acceptance; reducing the effects of anticipatory grief. Future research should also consider the relationship between perceived quality of life and the carer's own quality of life. Studies should aim to include homes with low regulatory ratings to capture a wider range of care homes and carers.

Recommendations

These findings suggest family and staff proxy ratings of quality of life cannot be used interchangeably. Substituting proxy reports may lead to false conclusions about a change or lack of change in quality of life. Collecting data about proxies may help to control for and explain variance in data. Where there are discrepancies, researchers should carefully consider which rating is most relevant to the outcome. Proxy reports may be considered to provide a valuable additional outcome: perceived quality of life. Collecting the opinions of all key stakeholders in the resident's life will maximize the chance of measuring improvements in care and quality of life.

Conclusions

A proxy rater's perception of quality of life is likely shaped by their experiences, their relational stance and their understandings. Staff tend to consider care whereas relative's evaluations often focus on loss. These findings enable us to better understand how and why staff rate the quality of life of the same individual as better than their family.

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Table 1: Staff Demographics (n = 12)

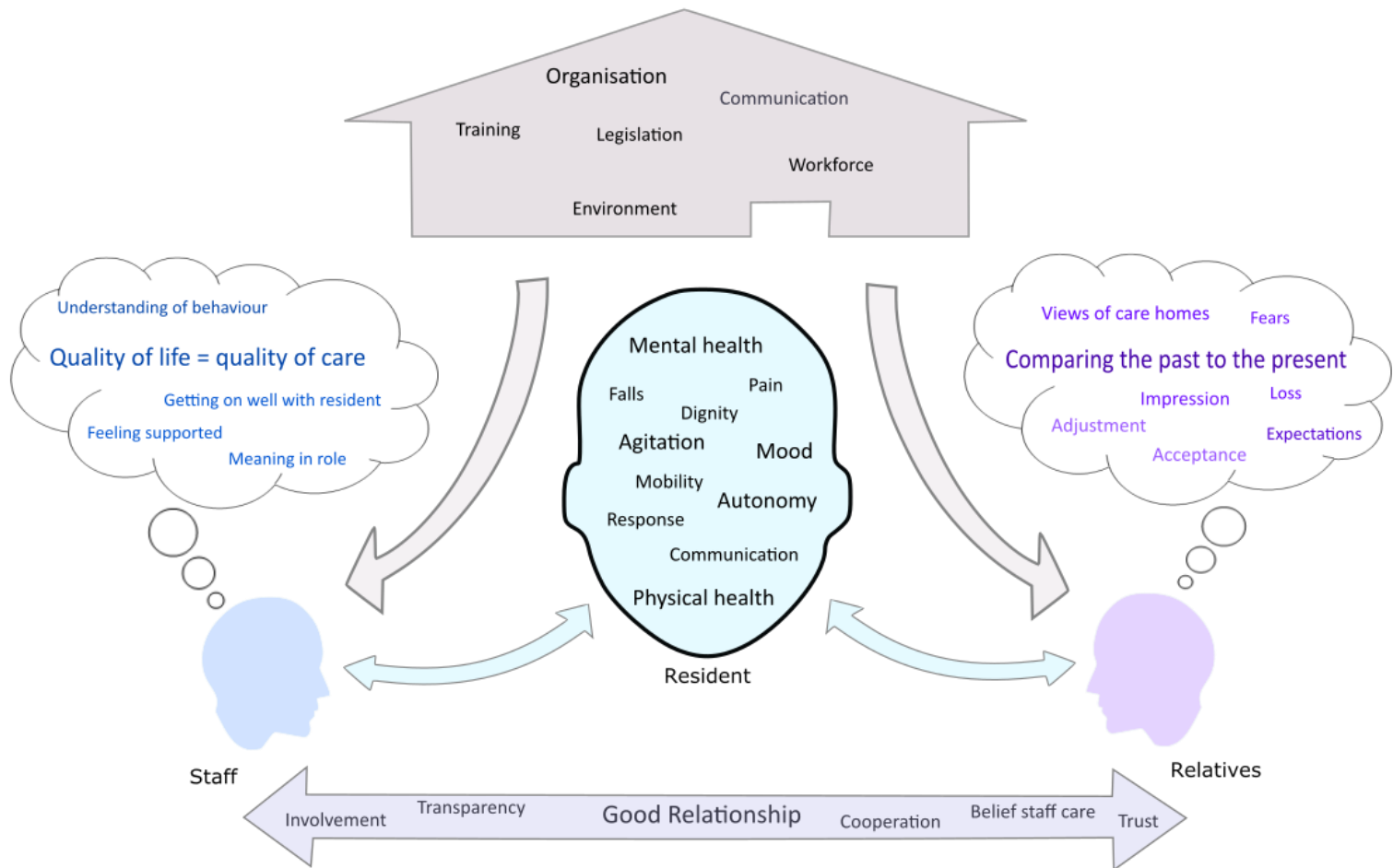
Staff characteristics (n = 12)	
Female	9
Age, years:	
18-34	4
35-45	4
46-56	4
Speak English as a first language	9 (75%)
Role	
Care Assistants	5
Senior Carers	3
Nurses	3
Manager	1
Ethnicity	
White British	5
Black British	4
Asian	3
Length of duration in care homes, years: median (IQR)	5.6 (1.9, 9.7)

Table 2: Relative Demographics (n = 12)

Family member characteristics		
Female		8
Age, years:		
	45-55	4
	56-65	4
	66-75	1
	76-85	2
	86-95	1
Relationship		
	Child or child-in-law	7
	Spouse	3
	Other	2
Ethnicity		
	White British	10
	Black British	2
Number of family visits per month (range)		4 (1 –15)

Figure 1: Visual representation of thematic matrix

† Bidirectional arrows present relational factors



Appendix 1 – Topic guide

Themes to explore

- The individual's perspective on the quality of life of the person with dementia
 - What is their perspective on the resident's current quality of life?
 - What shapes that perspective?
 - How did they come to a rating?
 - Have there been any changes in that person's quality of life and why that may have been.
 - What do they think is a good quality of life in a care home?
 - Is it possible to have a good quality of life in a care home? How might this be attained?

Family Carer & Staff Semi-Structured Interview Guide

Introduction: Thank you for taking part in this interview. I am interested in how you decided on your answers to our questions about [*resident's name*]'s quality of life. There is no right or wrong answers we are interested in exploring how staff and family arrived at their ratings.

- We asked how you feel [*resident's name*] would rate their quality of life overall. You chose [*insert answer: Very Good/Good/Fair/Poor*]. Could you tell me what made you pick that answer?
 - What sort of things did you consider in making that choice?
 - Have there been any changes in [*resident's name*] quality of life since they entered a care home?
 - If so, what changes?
 - What have caused these?
 - What would you consider to be a good quality of life in a care home?
 - Is it possible to have a good quality of life in a care home?
 - How do you feel [*resident's name*] would rate their quality of life now?